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ABSTRACT
                This annotated bibliography provides bibliographic
information and non-evaluative annotations of about 46 publications
based on research with families of children wit. disabilities and
authored by staff members of the Beach Center on Families and
Disability in Lawrence, Kansas. Citations are organized into sections
on book chapters, hearings and testimonies, journal articles, and
monographs. Within each section citations are listed alphabetically
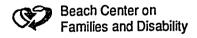by author. Publications date from 1985 through 1989. (DB)

Publications of Beach Center Researchers

Report AB-3

Julie Sergeant and
Harriet Shaffer (Eds.)

1989

This annotated bibliography is among a number of
bibliographies to be produced by the Beach Center at The
University of Kansas.

Beach Center on
Families and Disability

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ANNOTATED BIBLIOGRAPHY:

PUBLICATIONS OF BEACH CENTER RESEARCHERS

Sergeant, J. F., & Shaffer, H. E. (Eds.)

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INTRODUCTION

This listing describes publications based on research with families of children with disabilities. In these listings, one or more authors are staff members of The Beach Center on Families and Disability, a rehabilitation research and training center supported in part by the National Institute on Disability and Rehabilitation Research. Research projects span the life cycle and concentrate on families of persons with developmental disabilities, emotional disabilities, and technology support.

At this point in time, we are unable to provide copies of these book chapters, monographs, and journal articles due to existing copyright laws. These resources should be available at libraries associated with institutions of higher learning, or through interlibrary loan. In the future, we hope to have these documents available through the Beach Center.

The Beach Center is a research and training center with six fundamental beliefs about families related to positive contributions, great expectations, full citizenship, choices, strengths, and relationships. These beliefs are translated into a wide range of research, dissemination and training projects addressing family well-being across the lifespan. Newsletters and a publication catalog are available upon request. The Beach Center is unable to provide case management or direct services.

BOOK CHAPTERS

Barber, P. A., Turnbull, A. P., Behr, S. K., & Kerns, G. M. (1988). A family
systems perspective on early childhood special education.   In S. L. Odom & M.
B. Karnes (Eds.), <u>Early intervention for infants and children with handicaps:
An empirical base</u> (pp. 179-198).   Baltimore: Paul H. Brookes Publishing
Company.

> *From a family systems perspective, this chapter addresses   the
> reciprocal nature of the relationship between young children with
> exceptionalities and their families. The four components of the
> family systems framework provide the outline for the content, and
> vignettes and "fact or fable" statements illustrate the authors'
> points.*

Benson, H. & Turnbull, A. P. (1986).   Approaching families from an
individualized perspective.   In R. H. Horner, L. H. Meyer, & H. D. Fredericks
(Eds.), <u>Education of learners with severe handicaps: Exemplary service
strategies</u> (pp. 127-157).   Baltimore: Paul H. Brookes Publishing Company.

> *This chapter emphasizes the concept of individualization for families.
> The historical roles of parents are reviewed, and family systems
> theory is presented as a means of individualizing services.   In
> conclusion, implications for service delivery and research   are
> discussed.*

Bronicki, G. J., & Turnbull, A. P. (1987). Family-professional interactions.
In M. E. Snell (Ed.), <u>Systematic instruction of persons with severe handicaps</u>
(pp. 9-35).   Columbus, OH: Charles E. Merrill Publishing Company.

> *Beginning with the requirements and implications of parental   rights
> and   responsibilities under P.L. 94-142, this chapter offers a   broad-
> based   look at family-professional interactions.   Issues concerning
> parental   involvement are reviewed, and family systems theory is
> outlined and described.*

Brotherson, M. J., Backus, L. H., Summers, J. A., & Turnbull, A. P. (1986).
Transition to adulthood.   In J. A. Summers (Ed.), <u>The right to grow up: An
introduction to adults with developmental disabilities</u> (pp. 17-44).   Baltimore:
Paul H. Brookes Publishing Company.

> *Addressing the issues surrounding the process of transition   to
> adulthood, this chapter examines: (1) what transition means to   the
> young adult and his or her family, and the need for future   planning;
> (2) emerging adult needs and ways that families can plan to meet those
> needs; and (3) strategies for mobilizing a support system for families
> or young adults with a disability.*

Brotherson, M. J., Turnbull, A. P., Summers, J. A., & Turnbull, H. R. (1986). Fathers of disabled children. In B. E. Robinson & R. L. Barrett (Eds.), The developing father: Emerging roles in contemporary society (pp. 193-213). New York: The Guilford Press.

This chapter focuses on issues concerning fathers of children with a disability. Stress, personal and professional growth, self-esteem, and marital relations are all discussed. The authors include practical suggestions for professionals, including ideas for increasing the involvement of fathers, and professional resources such as books, organizations, and programs.

Knowlton, E., Turnbull, A. P., Backus, L. H., & Turnbull, H. R. (1988). Letting go: Consent and the "yes, but. . ." problem in transition. In B. Ludlow, A. P. Turnbull, & R. Luckasson (Eds.), Transitions to adult life for people with mental retardation: Principles and practices (pp. 45-66). Baltimore: Paul H. Brookes Publishing Company.

This chapter examines the increased role of decision-making in the lives of young adults. The authors argue that independence should be defined as one's personal choice of lifestyle, based on one's capacity and means to support that mode of living and one's personal values and preferences. Families and professionals are encouraged to allow young adults with mental retardation to make their own decisions to the greatest extent possible.

Summers, J. A. (in press). Assessing families for individualized family services plans. In J. Siders & M. Huch (Eds.), An ecological framework for team assessment: Infants and toddlers with critical needs. San Diego, CA: College-Hill Press.

Guidelines for the assessment of family strengths, needs, and outcomes for IFSP development are presented in this chapter. Citations of instruments to measure family's strengths and needs, an example worksheet to help determine family needs, and a case study are included.

Summers, J. A. (1988). Family adjustment: Issues in research on families with developmentally disabled children. In V. B. Van Hasselt, P. S. Strain, & M. Hersen (Eds.), Handbook of developmental and physical disabilities (pp. 79-90). New York: Pergamon Press.

This book chapter describes the historical perspectives of viewing families with a disability as villains, victims, or service providers, and examines the impact these assumptions have had upon research and the design of service programs. Methodological problems are discussed, and future directions for family research are suggested.

Summers, J. A., Behr, S. K., & Turnbull, A. P. (1989). Positive adaptation and coping strengths of families who have children with disabilities. In G. Singer & L. Irvin (Eds.), Support for caregiving families: Enabling positive adaptation to disability (pp. 27-40). Baltimore: Paul H. Brookes Publishing Company.

This chapter describes families who are said to have made a positive adaptation to their family member with a disability. Ways in which the experience of having a child with a disability may strengthen families, some cognitive coping strategies, and implications of these contributions and strategies for family support services are discussed.

Summers, J. A., Brotherson, M. J., & Turnbull, A. P. (1989). The impact of handicapped children on families. In E. Lynch & R. Lewis (Eds.), Exceptional children and adults (pp. 504-544). Glenview, IL: Scott, Foresman and Company.

Descriptions of the impact of a child with a disability on families provide professionals a solid foundation on which to base family-school partnerships in this book chapter. The authors utilize family systems theory to explore that impact and include a brief list of resources for parents or professionals.

Turnbull, A. P., Behr, S. K., Barber, P. A., & Kerns, G. M. (1988). The family of children and youth with exceptionalities. In E. L. Meyen & T. M. Skrtic (Eds.), Exceptional children and youth: An introduction (3rd Ed.) (pp. 81-107). Denver: Love Publishing Company.

This chapter in an introductory textbook for special education emphasizes the need for professionals to broaden their perspectives to include the family system of which the child with an exceptionality is a member. Each of the four components of the family systems framework is described.

Turnbull, A. P., Blue-Banning, M., Behr, S. K., & Kerns, G. M. (1986). Family research and intervention: A value and ethical examination. In P. R. Dokecki & R. M. Zaner (Eds.), Ethics of dealing with persons with severe handicaps: Toward a research agenda (pp. 119-140). Baltimore: Paul H. Brookes Publishing Company.

This chapter analyzes the values inherent in family research and intervention as a means for examining the ethical dimensions of professional practice. Varying perspectives from parents, persons with disabilities, and professional organizations are presented to encourage the reader to confront his/her own values.

Turnbull, A. P., Brotherson, M. J., & Summers, J. A. (1985). The impact of deinstitutionalization on families: A family systems approach. In R. H. Bruininks and K. C. Lakin (Eds.), Living and learning in the least restrictive environment (pp. 115-140). Baltimore: Paul H. Brookes Publishing Company.

Issues surrounding deinstitutionalization in the context of a family systems framework are examined in this chapter. The authors state that the components of the framework must be taken into consideration when determining the appropriate residential option for a family member with a disability. Suggestions are given for future research and policy considerations.

Turnbull, A. P., & Summers, J. A. (1986). From parent involvement to family support: Evolution to revolution. In S. M. Pueschel, C. Tingey, J. W. Rynders, A. C. Crocker, & D. M. Crutcher (Eds.), New perspectives on Down syndrome (pp. 289-306). Baltimore: Paul H. Brookes Publishing Company.

This chapter suggests a philosophical change in the orientation of service programs for children and youth with disabilities and their families. Family systems theory is used to support the shift from the professional's view of parents as the cause of their children's problems and as needing change to one of a service delivery system which changes and adapts to meet the varying needs of the diverse families in today's society.

Turnbull, A. P., Summers, J. A., & Brotherson, M. J. (1986). Family life cycle: Theoretical and empirical implications and future directions for families with mentally retarded members. In J. J. Gallagher & P. Vietze (Eds.), Families of Handicapped persons: Research, programs, and policy issues (pp. 45-65). Baltimore: Paul H. Brookes Publishing Company.

This chapter presents the family systems conceptual framework with a focus on the life cycle component of the system, reviews theoretical and empirical literature on the life cycle needs of families with members who have mental retardation, and suggests future research, intervention and policy directions aimed at strengthening family adaptation over the full life cycle.

Turnbull, H. R. (1988). Fifteen questions: Ethical inquiries in mental retardation. In J. Stark, F. Menolascino, M. Albarelli, & V. Gray, (Eds.), Mental retardation and mental health: Classification, diagnosis, treatment, services (pp. 368-377). New York: Springer-Verlag.

This chapter raises questions for professionals who work with people with mental retardation. Why these professionals provide certain interventions or services for people with mental retardation is examined, and the argument is presented that interventions often are self-serving for the professional rather than primarily beneficial to the person with a disability.

Turnbull, H. R. (1988). Summary of discussion and recommendations, Panel on Legal and Ethical Issues. In J. Stark, F. Menolascino, M. Albarelli, & V. Gray, (Eds.), Mental Retardation and Mental Health: Classification, diagnosis, treatment, services (pp. 378-380). New York: Springer-Verlag.

This chapter summarizes the contributions of several lawyers and one policy specialist to a conference on mental illness in people with mental retardation.

Turnbull, H. R. (1988). Ideological, political, and legal principles in the community living movement. In M. Janicki, M. Krauss, & M. Seltzer (Eds.), Community residences for persons with developmental disabilities: Here to stay (pp. 15-24). Baltimore: Paul H. Brookes Publishing Company.

This chapter sets out the principal legal, human service, and political ideologies that have justified the movement toward community-based services. The author issues certain warnings about the nature of these ideologies and their meaning for people with mental retardation.

Turnbull, H. R. (1988). Retardation, legal rights and the communal ideal: A reaction. In L. Kane, P. Brown, & J. Cohen (Eds.), The legal rights of citizens with mental retardation (pp. 54-73). Lanham, MD: University Press of America, Inc.

This chapter discusses the legal theories underlying the right to community services. The author argues that there is a trade-off between the values of freedom (liberty), equality, and community as law and policy seek to provide more community-based services.

Turnbull, H. R., & Brunk, G. L.(in press). The political philosophy underlying the community-services movement. In R. Shalock (Ed.), Quality of life. Washington, D. C.: American Association on Mental Retardation.

This chapter argues that the political philosophy tied to quality of life considerations that guides families professionals, and people with mental retardation should be one based on the "community." The author seeks to show how "creating community" is a philosophically grounded principle that should result in a higher quality of life for people with mental retardation.

Turnbull, H. R., & Guess, D., with Backus, L., Barber, P., Fiedler, C., Helmstetter, E., & Summers, J. A. (1986). A model for analyzing the moral aspects of special education and behavioral interventions: The moral aspects of aversive proceedings. In P. Dokecki & R. Zaner (Eds.), Ethics of dealing with persons with severe handicaps: Toward a research agenda. Baltimore: Paul H. Brookes Publishing Company.

This chapter develops an approach for analyzing the moral aspects of special education and behavioral interventions with children and adults who have mental retardation or other developmental disabilities. The authors' purpose is to highlight the moral dimensions of some interventions, point out the shortcomings of existing professional discussions on the subject, propose a model for analyzing the moral aspects of those interventions, and provide an illustration of that model.

Turnbull, A. P., & Turnbull, H. R.   (April, 1985).   Testimony to Select
Committee on Children, Youth, and Families, U.S. House of Representatives.

*This testimony discusses policy issues and programs which reject the
pathology model of families. The focus on how to help families be
successful includes four premises: (1) Families need help in attending
to the extraordinary needs of their child on a day-in and day-out
basis; (2) Families are infinitely diverse; (3) Balance is a key to
successful family life; and (4) Families change over the life cycle.*

Turnbull, H. R.   (September, 1989).   Statement of H. Rutherford Turnbull III on
incidence of discriminatory denial of medical treatment.   In Medical
discrimination against children with disabilities: A report of the U.S.
Commission on Civil Rights (Appendix B). Washington, D.C.: U.S. Commission on
Civil Rights.

*This statement addresses three topics regarding the right to medical
treatment for newborns with disabilities. The author asserts that
feder   action is needed to legislate against certain nontreatment
practices brought about by discriminatory attitudes of some medical
professionals; to monitor the role of Human Rights Committees and
Infant Care Review Committees in hospitals; and to expand support for
alternatives to nontreatment, such as adoption, foster-care placement,
and even interim institutionalization.*

Brotherson, M., Turnbull, A., Bronicki, G., Houghton, J., Roerder-Gordon, C., Summers, J. & Turnbull, H. (1988). Transition into adulthood: Parental planning for sons and daughters with disabilities. _Education and Training in Mental Retardation_, _23_(3), 165-174.

> This study examined aspects of parental planning for adult needs and the relationship of that planning to family functioning. The greatest needs identified by parents were residential, socialization, and employment. The paper discusses the results in terms of implications for professionals who work with families and future research directions.

Chandler, L. K., Fowler, S. A., & Lubeck, R. C. (1986). Assessing family needs: The first step in providing family-focused intervention. _Diagnostique_, _11_(3-4), 233-245.

> This article reviews a number of issues related to family assessment as part of their involvement in early intervention programs. The authors recommend the inclusion of family needs assessment as a first step in developing family-focused interventions. Suggestions for the design, selection, and use of needs assessment are made.

Drew, C. J., & Turnbull, H. R. (1987). Whose ethics, whose code? An analysis of problems in interdisciplinary intervention. _Mental Retardation_, _25_(2), 113-117.

> The authors discuss the problem of establishing a code of ethics in interdisciplinary fields. They ask whether or not professionals in the field of mental retardation should have a code of ethics.

Fowler, S. A., Chandler, L. K., Johnson, T. E., & Stella, M. E. (1988). Individualizing family involvement in school transitions: Gathering information and choosing the next program. _Journal of the Division for Early Childhood_, _12_(3), 208-216.

> This paper describes two Transition Planners which were developed to assist parents in planning their child's transition to elementary school. Parents completed rating scales and answered open-ended questions to identify family and child transition-related needs, levels of family involvement in transition planning, and areas of both family and school responsibility.

Fowler, S. A., Hains, A. H., Rosenkoetter, S. (in press). The transition between the Early Intervention Program and the Preschool Grants Program: Administrative issues. Topics in Early Childhood Education.

This paper briefly discusses the federal regulations for the Early Intervention Program for Handicapped Infants, Toddlers and Their Families, and the Preschool Incentives Grant Program. The focus is on the transition of children between these two programs and possible effects on state administration of the Preschool program and local agency administration. Recommendations for facilitating the family and child's transition are provided.

Johnson, T. E., Chandler, L. K., Kerns, G. M., & Fowler, S. A. (1986). What are parents saying about family involvement in school transitions? A retrospective transition interview. Journal of the Division for Early Childhood, 11(1), 10-17.

This interview of nineteen parents whose children attended three preschools and were presently attending public school was conducted face-to-face to find out what parents perceived as major issues during their child's school transition. Parents expressed both concern and satisfaction regarding their child's school transition, their role as decision-makers, and the effects of the transition on their family.

Petr, C., & Poertner, J. (1989). Protection and advocacy for the mentally ill: New hope for emotionally disturbed children? Community Mental Health Journal, 25(2), 156-163.

This article discusses a survey conducted to ascertain the potential effect of recent federal protection and advocacy legislation on the lives of children with mental illness. The findings indicate a strong potential, especially regarding efforts to improve community-based services.

Petr. C., & Spano, R. N. (in press). Services for emotionally disturbed children: Historical perspectives and contemporary opportunities for social work. Social Work.

This article examines the issues of institutionalization versus family life, relationships between social work professionals and clients, and current practices in light of the three following assertions: (1) institutions are the least advantageous response for most children; (2) community-based services provide opportunities for social workers to assist their clients; and (3) broad-based advocacy is needed to improve current services to children.

Summers, J. A., Dell-Oliver, C., Turnbull, A. P., Benson, H. A., Santelli, E., Campbell, M., & Siegel-Causey, E. (in press). Focusing in on the IFSP process: What are family and practitioner preferences? Topics in Early Childhood Special Education.

This study utilized focus groups to research opinions about the expected outcomes for families from early intervention programs and their preferences for the methods to be used in gathering information for the IFSP. Demonstrating sensitivity to families, acknowledging the family as the ultimate decision-maker, and respecting the diversity and individuality of families emerged as important considerations to the study participants.

Turnbull, A. & Bronicki, G. J. (1986). Changing second graders' attitudes toward people with mental retardation: Using kid power. Mental Retardation, 24(1), 44-45.

At age ten, Amy Turnbull wrote this article describing a study of second graders' attitudes toward people with mental retardation before and after the presentation of a lesson on mental retardation. Results as measured by the Wilcoxson Sign Test for Related Samples showed significant differences in the attitudes of the children.

Turnbull, A. & Bronicki, G. J. (1987). Using kid power to teach kids about mental retardation: A long-term follow-up. Journal of the Association for Persons with Severe Handicaps, 12(3), 216-217.

A follow-up to Turnbull & Bronicki, 1986, this study tested three hypotheses: (1) Positive changes in attitudes toward people with mental retardation will remain the same over a period of time, (2) Teaching kids about mental retardation will improve their attitudes toward people with mental retardation, and (3) Any kid with a positive attitude and with a good understanding of mental retardation can teach other kids. The results of the study support these hypotheses.

Turnbull, A. P. (1988). Accepting the challenge of providing comprehensive support to families. Education and Training in Mental Retardation, 23(4), 261-272.

This paper focuses on P.L. 99-457, Part H - Handicapped Infants and Toddlers. It briefly outlines the Part H goals and expectations for family support, suggests some possible outcomes for a comprehensive family support program, describes how these outcomes might be translated into assessment and service options, and concludes with a challenge for change in the future.

Turnbull, A. P., & Turnbull, H. R. (1985). Developing independence. Journal of Adolescent Health Care, 6(2), 108-119.

This article contrasts definitions and models of independence and autonomy, then discusses two prerequisites for independence: (1) access to the same opportunities of life as are available to people without disabilities, and (2) the capacity to participate in those activities. Finally, the authors examine issues in consent and decision-making.

Turnbull, A. P., & Turnbull, H. R. (1986). Stepping back from early intervention: An ethical perspective. Journal of the Division of Early Childhood, 10(2), 106-117.

This article examines three issues in the field of early intervention from an ethical perspective: (1) The use of the "fix-it" approach found in some applications of the developmental model, (2) The negative or pathological focus on the impact of a child with a disability on the family, and (3) The treatment and nontreatment of newborns with disabilities and the associated use of amniocentesis to identify birth defects during fetal development.

Turnbull, A. P., & Turnbull, H. R. (1988). Toward great expectations for vocational opportunities: Family-professional partnerships. Mental Retardation, 26(6), 337-342.

This article reviews the literature on parental attitudes towards supported employment and raises issues for the research community. The authors also note the role of expectations in service delivery and research.

Turnbull, H. R. (1987). BRI vs. Leonard. The Newsletter of The Association for Persons with Severe Handicaps, 13(5), 1-3.

Through an analysis of the court's decision on aversive interventions in the case of BRI vs. Leonard, the author explains why the case is a "victory" for those who oppose such interventions.

Turnbull, H. R. (1987). [Review of Federal policy toward mental retardation and developmental disabilities]. American Journal of Mental Retardation, 92(3), 322-323.

This positive book review of a work by David Braddock focuses on federal policy options in the area of mental retardation and developmental disabilities. Turnbull cautions, however, that state, local, and private expenditures as well as federal influences need to be considered when looking at mental retardation and developmental disability issues as a whole.

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Turnbull, H. R., Guess, D., & Turnbull, A. P. (1988). Vox populi and Baby Doe. Mental retardation, 34(4), 261-272.

Through an analysis of written responses to the U.S. Department of Health and Human Services regarding federal funding to hospitals that discriminate against newborns with a disability, this study found that responses almost unanimously supported the proposed "Baby Doe" regulations. The content analysis and additional information related to the perceived need for early intervention and adoption services are reported and discussed.

Turnbull, K., & Bronicki, G. J. (1989). Children can teach other children. Teaching Exceptional Children, 21(3), 64-65.

This article describes the experiences of the principal author, a third grader, as she taught classmates about her friend Kevin, who has severe mental retardation and needs dialysis five times a day. She tested the hypothesis that teaching will help children know more about what to do with and be more comfortable around someone with a severe disability.

Winton, P. J., Turnbull, A. P., & Blacher, J. (1985). Expectations of and satisfaction with public school kindergarten: Perspectives of parents of handicapped and non-handicapped children. Journal of Division of Early Childhood, 9(2), 106-117.

This study surveyed parents of children with and without disabilities who attended mainstreamed public school kindergarten classrooms. Results indicated group differences between parental expectation of and degree of satisfaction with their child's program, and similarities in views on parent involvement.

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Report of a symposium on adult status for youths with disabilities. Turnbull, H. R. (1988). Paris, France: Center for Research and Innovation, Organization for Economic Cooperation and Development.

This report discusses barriers to adulthood and adult status that face people with disabilities. Methods of overcoming these barriers as implemented in the Scandinavian countries, Great Britain, and the United States are discussed. Responses of families to the adulthood of their children with disabilities, and some steps that policy makers and families can take to ensure adult status for people are examined.

The Latin American family and public policy in the United States: Informal support and transition into adulthood. Turnbull, H. R., & Turnbull, A. P., (1987). New York: World Rehabilitation Fund.

A World Rehabilitation Fund (WRF) Grant funded this study and report on the Latin American family and its adaptations, coping strategies, and use of informal support in families with a member who has a disability. The Latin American family and its traditions, attitudes, and behaviors with respect to the transition of the member with a disability from adolescence to adulthood is also addressed.

Stress and coping in families having a member with a disability. Turnbull, A. P., Summers, J. A., Backus, L., Bronicki, G. J., & Goodfriend, S. J. (1986). Washington, D. C.: NARIC Rehabilitation Research Review.

This literature review utilizes Hill's (1949) ABC-X model of stress and coping to analyze sources of stress in families who have a member with a developmental disability, as well as family resources and perceptions that may mitigate the effects of those stressors. Implications and recommendations for future research are discussed.

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